



## DOCTORS OF THE WORLD-USA

### DEINSTITUTIONALIZATION AND INCLUSION PROJECT KOSOVO

#### FINAL NARRATIVE REPORT DECEMBER 2003

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Doctors of the World-USA's *Deinstitutionalization and Inclusion Project* was launched in December 2000 and received USAID support from 1 January 2003 to 30 September 2003, through Award Number 167-G-00-03-00103-00. The project aims to:

Establish sustainable, community-based services; facilitate community and family integration for 16 children deinstitutionalized from Shtime Institution and the Pristina Elderly Home; and, in the process, develop protocols of best practices that can be replicated and supported by communities in the region.

The project received initial funding from UNICEF and focused on deinstitutionalizing the 16 children residing in the two closed institutions of Kosovo. WHO, the UNMIK Ministry of Social Welfare (MSW), and other agencies in Kosovo were charged with the creation of community-based care. The creation of such services was hindered, however, by lack of political will. Recognizing that the achievements of the first phase of the Deinstitutionalization and Inclusion Project were threatened by the lack of UNMIK commitment to true deinstitutionalization, Doctors of the World-USA (DOW) requested USAID support to continue its critical lobbying and community-based activities.

#### PROJECT ACHIEVEMENTS

**Objective 1:** Further develop community-based knowledge and resources – including professional, local NGO and family skill building and enhanced access to support and rehabilitation services.

DOW further developed community-based knowledge and resources through the following activities:

- Developed Community Advisory Boards in Shtime, an Albanian majority area, and in Gracanica, a Serbian and Roma minority area, in the first quarter. Members of the Community Advisory Boards (CABs) include NGO representatives, parents of children with disabilities, and related professionals. CABs provide oversight to DOW activities and facilitate integration of the homes into the greater communities. During the project period, the CABs met once per quarter and held one joint meeting to discuss issues common to all CABs.

- Conducted mobile assessments of children living with disabilities in Gracanica and Shtime and created concomitant community services plans.
- Developed a parent support group in each area. The 40 members were primarily those identified by the above assessment. DOW provided ongoing logistical, technical, and financial support to these groups, which met twice per month.
- Distributed booklets to raise awareness about people with disabilities to schools, community groups, and municipal officials in both Gracanica and Shtime.
- Engaged an international therapeutic recreation consultant who trained all house staff (as well as local staff of DOW's informal partner, the Vietnam Veterans of America Foundation) in working with parents of disabled children on therapeutic and advocacy issues.
- Organized the training of approximately 40 parents of children with disabilities in basic care and social needs of disabled children. The trainings were provided by the Kosovar Medical Director of Handikos, and were held in Gracanica and Shtime.
- In cooperation with the Mental Disability Advocacy Center, HandiKos, and the Vietnam Veterans of America Foundation, organized a 3-day training in Pristina – *Disability Services in Kosovo: A Call to Action*. Training topics included human rights and mental disabilities, social welfare in Kosovo, health reform in transition countries, medical versus rights-based models of care, patients' rights, and community-based rehabilitation. The 70 training participants included doctors, nurses, social welfare professionals, NGO advocates, parents, and special education teachers.
- Lobbied effectively with the MSW regarding the provision of timely and correct provision of food for the home in Gracanica, staff salaries, and rent. DOW involved representatives of USAID and the World Bank in these efforts.
- Broadcast regular destigmatization radio spots on Serbian language radio stations (four times/day).
- Transferred the DOW-run resource center in Shtime from the HandiKos Office to the community-based home in Shtime, and continued to provide speech, physiotherapy, and sports rehabilitation to children from the community. DOW provided transport to children whose families lacked a vehicle. In order to encourage families to bring their children to the Shtime Home (which, as it houses children from the Shtime Institution, is highly stigmatized), DOW met with health, municipal, school, and families of children with disabilities to explain the importance of inclusion.

As a result of the above activities, the following **outcomes related to Objective 1** were achieved:

- ➔ Six of the children assessed by the mobile team began to make regular visits to the HandiKos Rehabilitation Center in Ferizaj (transport was provided by HandiKos), and 3 others were referred to medical care.
- ➔ Eleven of the children assessed in Gracanica began tutoring and speech therapy twice per week, an activity supported at the community-based home in Gracanica.

- ➔ For distribution at the training conference, DOW developed and translated the first ever Albanian and Serbian *Glossary of Disability Issues*. The glossaries are now available at both children's homes, the community resource centers, and the seven Kosovar Community Mental Health Centers, providing a fundamental and critically needed resource to professionals and interested community members.
- ➔ As a result of DOW lobbying, the Shtime resource center was moved to a sustainable public entity – the community-based home in Shtime. The resource center's activities will thus continue beyond DOW involvement, providing needed services to isolated children with disabilities living in the community and increasing community integration of the children's home.
- ➔ Two sustainable parent support groups were created, which continue to meet on a regular basis. These parents provide support to one another in negotiating access to public services and in addressing obstacles to community integration.
- ➔ By the fourth quarter, the MSW was supplying funds and other inputs in a timely fashion without DOW prompting.

**Objective 2:** Evaluate the project with an aim toward developing guidelines/protocols for deinstitutionalization and community inclusion of disabled children throughout the region.

DOW evaluated the project and worked toward developing guidelines/protocols for deinstitutionalization and community inclusion through the following **activities**:

- Developed Deinstitutionalization Protocols that can be used by governmental and non-governmental agencies working throughout Southeastern Europe.
- Established a relationship with a volunteer psychiatric nurse in New Hampshire who responded to house staff questions and reviewed and commented on the existing DOW deinstitutionalization protocols.

As a result of the above activities, the following **outcomes related to Objective 2** were achieved:

- ➔ Established relationships with agencies working on disability issues throughout the region, who are reviewing the protocols and discussing possible program collaboration.

**Objective 3:** Provide psychosocial and rehabilitative services to children to increase independent living skills and options for community integration.

DOW provided psychosocial and rehabilitative services to children to increase independent living skills and options for community integration through the following **activities**:

- Beginning in the second quarter, DOW resource centers in both communities provided an average of 14-20 children per week with speech therapy, tutoring, and physical therapy (apart from those included in the assessment noted above).

- Cooperated with the Vietnam Veterans of America Foundation in providing ongoing sports therapy to the children in the two community-based homes, as well as to children who had been identified as part of the DOW mobile assessment.

As a result of the above activities, the following **outcomes related to Objective 3** were achieved:

- ➔ Almost 40 children, who previously had *no access* to physiotherapy, speech therapy, and special education, gained access to all three. These children, also for the first time, had structured opportunities for creating social connections with other disabled children.
- ➔ The community-based home in Shtime was further integrated into the community.

**Objective 4:** Develop opportunities for reunification with families of origin or foster family placement.

DOW developed opportunities for reunification with families of origin or foster family placement through the following **activities**:

- Organized Easter holiday homestay visits (with members of families of origin) for two children from the two homes.
- DOW insisted on DNA testing to determine whether or not a child, who the MSW wanted to place with an alleged family of origin in Serbia, was indeed a biological child of this family. The test was conducted and the child was found to not be related to the family in Serbia. She remains in the community-based home in Gracanica.

As a result of the above activities, the following **outcomes related to Objective 4** were achieved:

- ➔ As a result of DOW lobbying, the exchange of photographs prior to initiating first contact between children and potential families of origin became procedure. In the event that these photographs raise questions, DNA testing will be initiated.
- ➔ The process of potential adoption by family of origin was advanced for two children.

## OBSTACLES

Primary obstacles encountered by DOW during the USAID-funded project period included pervasive stigma and the ongoing lack of community support for inclusion of persons with disabilities, including resistance from educational and health service providers. While DOW activities aimed to change these conditions, changing widespread and long-held beliefs and behavior – particularly with limited funds – requires longer-term planning and interventions.

The overall efficacy of DOW's efforts was further limited by the lack of UNMIK and MSW commitment to community-based care. Indeed, DOW lobbied constantly to have the two homes

formally divorced from the Shtime Institution, and this request – which is based on international best practices – was repeatedly denied. UNMIK and the MSW felt that keeping the two homes under the aegis of the Shtime Institution would minimize perceived threats to employment of institution staff and facilitate the homes' administration.

#### **PRIORITIES FOR NEXT YEAR**

Doctors of the World-USA will increase its focus on community-wide activities as DOW further transfers all responsibility for the two homes to the MSW. This strengthened focus on community activities will include continued and expanded destigmatization campaigns, further support of the CABs and parents' groups, advocating for increased government commitment to community-based care, and efforts to facilitate community integration for the 30 children using DOW-provided habilitation services. DOW has already received funding from CIDA and the Oak Foundation, and has additional proposals pending.